



Technical Brief Disposition of Comments Report

Research Review Title: *Assessment Tools for Palliative Care*

Draft review available for public comment from August 25, 2016 September 21, 2016.

Research Review Citation: Aslakson R, Dy SM, Wilson RF, Waldfogel JM, Zhang A, Isenberg SR, Blair A, Sixon J, Robinson KA. Assessment Tools for Palliative Care. Technical Brief No. 30 (Prepared by Johns Hopkins University under Contract No. 290-2015-00006-I.) AHRQ Publication No. 14-17-EHC007-EF. Rockville, MD: Agency for Healthcare Research and Quality; May 2017. www.effectivehealthcare.ahrq.gov/reports/final.cfm. doi: <https://doi.org/10.23970/AHRQEPCTB30>.

Comments to Research Review

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The tables below include the responses by the authors of the review to each comment that was submitted for this draft review. The responses to comments in this disposition report are those of the authors, who are responsible for its contents, and do not necessarily represent the views of the Agency for Healthcare Research and Quality.

#	Commentator & Affiliation	Section	Comment	Response
1	Key Informant #1	General Comments	<p>In such an exhaustive search it is almost inevitable that domains may have questionable elements (e.g., the WALT as an ethical/legal document is open to question), scales will be missed and not all relevant statistics will be presented. Nevertheless, it seems worth mentioning some possible oversights (unless this reviewer missed these measures or misunderstood why they would not be relevant):</p> <p>SCID -- Structured Clinical Interview for the DSM is a better established assessment tool than the other rater administered depression and anxiety measures mentioned. The Beck Depression (Anxiety) Inventories, the Impact of Events Scale Revised is not included but Horowitz' IES is. Sharon Inouye's Confusion Assessment Method (CAM) for delirium and Meg Campbell's RDOS -- respiratory distress for patients on a ventilator. The PEACE scale that assesses patient's ability to accept and struggle with cancer (perhaps too specific) the Stressful Caregiver Adult Reactions to Experiences of Dying (SCARED) scale which predicts many things like hospice enrollment and length of stay, the United States Acculturation (USA) scale to assess cultural influences on lot of things, including where a person wants to die and, of relevance, if they would want to go "home". There are several spirituality measures including Ken Pargament's or Carver's R-COPE or the NIA/Fetzer Multidimensional Measure of Religiousness, the Koenig Religious Coping Index, for example.</p>	<p>Thank you for your comment. We appreciate that tools may be classified differently. We used how the tools had been classified in prior reviews.</p> <p>We appreciate the suggestions of tools and address each below:</p> <p>We have clarified the definition of assessment tools in the introduction: "An assessment tool is defined as a data collection instrument (generally a scale, questionnaire or survey) that has been psychometrically evaluated and is completed by or with patients or caregivers..." The SCID, and delirium and respiratory distress observation scales (completed by providers) did not meet inclusion criteria.</p> <p>Given the use of the National Consensus Project to define palliative care domains, acceptance of cancer (PEACE scale) and acculturation were not in scope. We have added to the limitations, "Using the National Consensus Project Guidelines as a framework for the domains and limiting to tools evaluated in palliative care populations excluded some types of tools that may be relevant in some applications in palliative care populations."</p> <p>For the additional caregiver and spirituality measures that you identify: most of these tools have not been evaluated in palliative care populations and therefore were not included in the report. The reviews for these topics (caregiving and spirituality) identified a large number of measures but according to those review authors, very few of the tools were tested in palliative care populations. Only tools identified as tested in palliative care populations were considered in our report.</p> <p>SCARED was not in the scope of caregiver tools that were included in the systematic review that we included, which focused on caregiver burden, strain and quality of life. We have added to the limitations section that not all aspects of caregiving were included.</p> <p>We have added to the limitations: "Few spirituality tools have been assessed in palliative care populations. Tools including the Spiritual Well-Being (FACIT-Sp) tool, the Spiritual Well-Being Scale, and the Koenig Religious</p>

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				<p>Coping Index were therefore not included, but may be useful in palliative care research.”</p> <p>Thank you for the comment that many of these scales have multiple versions. We have now noted this in the limitations of the review: “Finally, some scales noted in the review also have multiple versions that were not always noted in our sources, and future use of these tools should search for different versions that might be more appropriate.”</p>
2	Key Informant #1	General Comments	<p>Then there are the psychometric statistics to evaluate the measures. Relevant issues include face and content validity, incremental validity, and sensitivity and specificity of the tool with respect to a criterion standard.</p> <p>No large project such as this can do everything and a lot of great work has been done, but would be interested in learning if there was a reason to exclude the mentions above.</p>	<p>We have added to the methods: “We abstracted information based on key elements from the National Quality Forum criteria for Patient Reported Outcomes in Performance Measurement,²² which were developed by an expert panel and are based on scientific acceptability (i.e., validity, reliability, and responsiveness) and usability (i.e., verification that the tool has been used, is feasible, and provides useful information for palliative care in the areas of clinical practice, quality indicators, or evaluation of interventions).”</p>
3	Key Informant #1	Clarity and Usability	<p>It might have been useful to make clear, simple recommendations of what measures would be recommended or provide scores/grades for evidence in support of a given measure.</p>	<p>Thank you; another organization is planning to make recommendations based on this report. We have added to the discussion, “Other organizations may use the survey of tools in this report to provide more specific recommendations for tools; consensus work to recommend tools would be helpful for researchers in palliative care.”</p>
4	Peer Reviewer #2	General Comments	<p>Overall, this report is outstanding. It will serve as a tremendous resource for those who utilize palliative care assessment tools in clinical care, quality efforts or research, as well as for measure developers. As is appropriate for a technical brief, it clearly assesses and summarizes the issues and identifies the methodologic problems that need to be resolved. One recommendation is that the report make clear in the text that the scope includes all ages (including pediatrics), all diseases and all settings. This information is in Appendix F (Inclusion Criteria), but is not inherently obvious in the text. It seems that it would be particularly relevant to comment on the extent to which existing metrics/tools apply to the pediatric population.</p>	<p>Thank you. We have added, “We included all age groups, populations, and settings.”</p> <p>We have included a sentence in the limitations section of the discussion: “We did not identify any high-quality reviews addressing tools for use in the pediatric population”. And in future research we have emphasized that a review in pediatrics would be valuable.</p>
5	Peer Reviewer #2	Background	<p>The background clearly states the context, gaps and purpose of the manuscript. One suggestion - page 1, bottom of last paragraph -- another challenge is lack of consistency in use</p>	<p>Thank you. We have added this to the next steps section, “Further research should also address use of assessment tools across settings and populations”.</p>

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			of assessment tools across settings, populations and settings, which hampers the ability to permit comparisons. More consistency in use of palliative care assessment tools would make it possible to compare outcomes across interventions.	
6	Peer Reviewer #2	Guiding Questions	The guiding questions are clearly stated.	Thank you for your comment.
7	Peer Reviewer #2	Methods	Overall, the methods are clearly stated. One suggestion is to describe how the key informants were identified. Were they a convenience sample? People whom the authors knew? Recommended by others? Understanding how the key informants were identified will lend legitimacy to the methods.	We have clarified this sentence in the methods: "We selected the Key Informants to give a balanced perspective on different domains, and applications of palliative care tools; we identified nine Key Informants including two caregivers. The role of the Key Informants was to inform the conduct of the review."
8	Peer Reviewer #2	Findings	The key informant interviews add valuable perspective and there is good face validity to the findings from the key informant interviews.	Thank you for your comment
9	Peer Reviewer #2	Findings	It is not clear how issues related to proxy response (e.g. for cognitively impaired patients, or patients who are too ill to provide self-report) and to pediatric patient populations were addressed in the findings. Given the high prevalence of these issues in the palliative care population, it seems that it would be valuable to specifically call out the extent to which these issues are addressed and where the gaps remain.	We have included a sentence in the limitations section: "We did not identify any high-quality reviews addressing tools for use in the pediatric population". And in future research we have emphasized that a review in pediatrics would be valuable. We addressed the issue of proxy response in several ways – in the detailed appendices, in the column "Form completed by" which included proxy, and in the column inter-rater reliability. Unfortunately, these issues were rarely reported and therefore we were unable to draw conclusions on how often they are addressed and where gaps remain.
10	Peer Reviewer #2	Findings	In the "Single Domain" section (page 8) it is not clear why the physical symptom focus is limited to dyspnea and pain. While the report states that "all physical symptoms was beyond the scope of this brief", it doesn't explain why dyspnea and pain were selected. For example, fatigue is a more prevalent symptom in the palliative care population. Why was it excluded? There likely is valid reasoning, but without an explanation, the reader is left wondering why these 2 symptoms were the focus.	We have taken out the language that ""all physical symptoms was beyond the scope of this brief" and noted that all symptoms were included in multi-domain tools (classified under quality of life). We have added fatigue to this section. We have reworded to clarify that "the focus for symptom-specific tools was limited to dyspnea, pain and fatigue, based on their selection for multiple prior systematic reviews of assessment tools."
11	Peer Reviewer #2	Summary and Implications	The summary and implications follow from the data presented and are clearly stated.	Thank you for your comment.
12	Peer Reviewer #2	Next Steps	The next steps are clearly delineated.	Thank you for your comment.
13	Peer Reviewer #2	Clarity and Usability	The report is well structured and organized, with a good balance between the summary provided in the text and the detail provided in the appendices. The conclusions will	Thank you for your comment.

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			definitely inform and guide future research.	
14	Peer Reviewer #3	General Comments	Thank you for the opportunity to review this important and timely report. The authors are commended for their efforts to provide an overview of key issues in this area, discuss concerns and the existing research to address them.	Thank you for your comment.
15	Peer Reviewer #3	General Comments	Overall, the Technical Brief provides some guidance for future reviews and a general framework for ongoing research.	Thank you for your comment.
16	Peer Reviewer #3	General Comments	The report required a lot of switching from the text to looking at the Appendices to obtain either more or complete information. Supplemental information should go into the Appendices, but there were instances when the authors would want to consider adding relevant information succinctly summarized in the body of the text.	We appreciate this comment. We balanced the need for a succinct technical brief that is usable for most readers with more detail in appendices for those readers who wish to have these details.
17	Peer Reviewer #3	Background	Overall, the background describes the problem that is to be addressed in this report.	Thank you for your comment.
18	Peer Reviewer #3	Background	Page 1 Table 1 refers to National Consensus Guidelines Domains for Quality. Here topics like "ethical and Legal" include care planning--however; this area encompasses much more. In the definition of terms on page 10/144, it would be useful to describe how this report considers defining this area.	We did not find any studies of any other types of psychometrically-evaluated assessment tools that fit into the "ethical and legal" category. We have clarified in Table 1 by changing from "e.g., care planning" to "i.e., care planning".
19	Peer Reviewer #3	Background	Overall--this report needs to be clear about whether the pediatric population (including adolescents and young adults are included). There is an expert in pediatrics mentioned as being a key informant, but no mention of pediatrics, tools, or lack of tools afterwards. Why have an expert in pediatrics if this is not the focus age group of the review.	We have added to the methods (end of data collection): "We included all age groups, populations, and settings." However, we did not identify any eligible sources in our searches focusing on pediatric tools. We have added to next steps, "A high-quality systematic review focusing on the use of tools in pediatrics would also be useful."
20	Peer Reviewer #3	Background	Page 2 (10 of 144). Line 46--it was unclear if definition of assessment tool included questionnaires, surveys, etc. These may be used to collect information rather than "evaluate" --examples of tool types or descriptions would have been useful to guide evaluating the data in later sections.	We have expanded the definition as suggested: An instrument (generally a scale, questionnaire or survey) completed by or with patients or families that has been psychometrically evaluated and is used to collect data at the individual patient level." Examples are in the 2 nd paragraph of the introduction: "Assessment tools may include patient and caregiver reports of physical symptoms (e.g., pain and dyspnea), mental health issues (e.g., depression), caregiver outcomes (e.g., quality of life and burden), and processes of care (e.g., communication and continuity)"
21	Peer Reviewer #3	Background	Page 2 (10 of 144). Definition of terms. The definition of palliative care explains what palliative care is, but there is ambiguity around "serious, advanced illness". Many tools are designed for e.g., oncology, renal, or other populations. What	Based on discussion with the key informants, we used the definition from "Dying in America". We used the definitions as applied by each systematic review of tools of palliative care. We did abstract the population studied as "palliative

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			constitutes serious? Advanced? How did the tools align to stage of a condition/illness and symptoms?	care” for each tool (in the appendices) but this often did not include stage or symptoms.
22	Peer Reviewer #3	Guiding Questions	The guiding questions were comprehensive. The authors noted the use of one additional section for multidimensional tools.	Thank you for your comment.
23	Peer Reviewer #3	Guiding Questions	General Comment. In looking at the results sections and relating back to the Guiding Questions, I found many of these guiding questions were varied--and many times not addressed. When data do not exist specific to a question, it would have helped a comprehensive response to the tasked Guiding Questions, to indicate no data were available for Questions and sub-parts.	<p>We have included a section at the end of the methods to be clearer how Guiding Questions were addressed:</p> <p>“Data Presentation</p> <p>We developed evidence tables based on the domains and assessment tool contexts, settings, and populations. To address the Guiding Questions, we performed the following tasks:</p> <ul style="list-style-type: none"> • Guiding Question 1: we catalogued and compiled tool characteristics by domain • Guiding Question 2: we described the current state of research for tools in each domain • Guiding Question 3: we catalogued the current state of research on use of the tools for evaluation of interventions, clinical care, and quality measurement (quality indicators) • Guiding Question 4: we provided a summation of relevant issues and gaps”
24	Peer Reviewer #3	Methods	The Methods section overall clearly described how data for this report were gathered and integrated.	Thank you for your comment.
25	Peer Reviewer #3	Methods	Page 4 Systematic Review Search is thorough.	Thank you for your comment.
26	Peer Reviewer #3	Methods	Page 4 (12 of 144). Discussions with Key Informants. Information in this section was sparse and required going into to Appendix C-D to grasp how information was gathered and how balance and thoroughness was ensured. The section was not clear as to the level of engagement with the Key informants (and then a later outside expert) and their role in shaping the report.	<p>We have added to the methods on Key informants: ...”we had 1.5 hour long calls with two groups of Key Informants: caregivers and clinicians/researchers.”</p> <p>We have added language to the next steps section indicating that further consensus work with a broader group of stakeholders would be a beneficial.</p> <p>Regarding the specifics of who were the key informants, we did not have any patients and we have clarified these “caregivers” throughout. We have removed the term “patient advocate”.</p> <p>We have added the number of key informants to the</p>

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			<p>The section is very concise--but that may be a limitation as to how Key Informants were selected and the information obtained.</p> <p>For example, it is unclear if patients themselves were informants (see later discussion on "patient advocates."</p> <p>Did not have information on numbers of Key Informants until page 6 Results (2 caregivers, 7 providers).</p> <p>It would have been useful, given the breadth/scope of the definition of palliative care, to have known more about the caregivers "for patients who had received palliative care" (line 12). Were they spouses, siblings, friends, etc.? Were they elderly or young adults? Did they provide direct care to their loved ones (e.g., care giving at home) or caregivers with support, e.g., hospice? Extent and length of their caregiver experience (e.g., through end of life and bereavement or early palliative care experiences in early stages of advanced illness)? What were their loved one's serious illness? What level of palliative care was received, by whom and where? Understanding the informers may impact the conclusions of the responses of the informers cited in the report text.</p> <p>It was unclear what "quality experts" means (line 13). These persons should be defined.</p> <p>"</p>	<p>Methods section. We have also added in a sentence on the role of the Key Informants: "The role of the Key Informants was to inform the conduct of the review."</p> <p>Regarding the background information on our caregiver key informants we appreciate the level of detail requested by this reviewer but they were informants and not research subjects. We cannot provide personal health information.</p> <p>We removed the terms "outcomes research", "quality experts", and replaced "clinical trials" with "evaluation of interventions" to better fit with the language of the report.</p> <p>We have clarified in methods how the key informants were selected: "We selected the Key informants to give a balanced perspective on different domains, and applications of palliative care tools." We chose experts on tools since this was the purpose of the report. We clarified in the results that these were provider/researchers.</p> <p>The key informants are named in the final report.</p>

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			<p>Page 6 in the Results Section lists "providers" as having expertise in areas in oncology, pediatrics, critical care, health services research, outcomes research , pall care quality measures, clinical trials, and assessment tool development. It would have been useful if an expert was more clearly chosen to align skill sets with the different domains (e.g., a psychologist/psychiatrist consultant to palliative care or a social worker, a palliative care chaplain/spiritual/religious expert, a legal expert, an ethics expert, etc.).</p> <p>Clinicians" on line 12 is not defined. Were "clinicians" M.D.'s, oncologists, geriatricians? Nurses? Hospice Nurses?</p> <p>The use of "researchers" is broad and not clear from page 6 why "clinical trials" researchers would necessarily be best choices for this project.</p> <p>What is "outcomes research?"</p> <p>The lack of description of Key Informants in the Technical Report suggests that, perhaps, the individuals selected may have not best matched to provide input on the domains required and, that is difficult to ascertain if the use of Key Informants is valid. It may be important to discuss how selected, vetted, etc., in the Methods section to provide how</p>	

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27	Peer Reviewer #3	Methods	<p>these methods were selected.</p> <p>In reviewing Appendix C (Key Informant Questions), the title indicates "Patient Advocates" on line 7. The text on page 4, however, does not describe Key Informant "patient advocates." Later, on page 6, line 14 there is a title of "Caregiver Advocates." This inconsistency is concerning.</p> <p>The term 'advocate' suggests a greater level of involvement of the individual in pursuing palliative care support rather than obtaining information from typical caregivers. The few caregivers used suggests that the Informants may have been a narrow response--possible bias.</p> <p>Question 3 on the questionnaire for this group delineates on line 20, page C-1 ". . .what do doctors and palliative care staff". Stating two different groups is confusing given the descriptions of the Informants. Are the 'palliative care staff' not 'doctors'? Is the question meant to parse out Informant differences between primary physicians (and not other care staff) and the palliative team regarding use of palliative care tools? Do non-palliative care professionals use palliative care tools--why state 'doctors'? Question 4 asks patient advocates to determine if something is missing from the domains---but it seems questionable if the patient population as a whole would be knowledgeable about this, e.g., are patients</p>	<p>We have changed the wording from "advocate" to caregivers in the body of the report. Both were caregivers reporting on patient experiences. 4 r</p> <p>We clarified the role of key informants in the methods: "The role of the Key Informants was to inform the conduct of the review."</p> <p>Thank you for your detailed feedback on questionnaire Questions 3 and 4. Unfortunately, as we have already administered these questions to the key informants, we are unable to make the modifications you suggest.</p> <p>Regarding your insights from Question 4, we agree that patients and caregivers may not be able to comprehensively comment upon what is missing from the domains, but we felt that it was important to solicit their opinions on all aspects of the project given their role as described above. They did not have much feedback regarding this question.</p>

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			knowledgeably about psychiatric aspects of care, ethical or legal aspects of care? Thus, it would have been important to describe whether those selected for this key informant section would have been knowledgeable enough to address the question.	
28	Peer Reviewer #3	Methods	Page C-2 Questions for the Providers--asks in Question 7, line 57, "Are there key research gaps regarding palliative care assessment tools?" I am not confident that clinicians (as interpreted from the descriptions in the text) would be sufficiently knowledgeable about the research literature, let alone research gaps---or were the experts selected only if both provider and researcher? How many Informants were 'researchers'---a small n would create concern regarding the limitation of the information provided.	We clarified in the results that these were clinician/researchers, and clarified their role in the Key Informants section of the methods: "The role of the Key Informants was to inform the conduct of the review."
29	Peer Reviewer #3	Methods	Page 5, lines 22-25. Under Supplemental Literature, the authors state that additional information was provided by a single outside expert who identified information about evaluation of interventions where palliative care tools are used. There is a citation following this statement to a U.K. website with authors. There is no information why a sole source was used, the capability of a sole source to provide this information--and why a non-U.S. single expert was used to discuss where tools are used--which could mean in the U.K. Explanations should be provided in the text on why this method was selected and information provided that would support that this expert was qualified.	We have reworded throughout the report that this is an unpublished systematic review (the citation is the protocol since the review has not yet been published).
30	Peer Reviewer #3	Findings	The Key Informant area for caregiver advocates was sparse in regards to information without descriptions of what was meant by the responses. While the Report is to be concise and information-driven, there are many gaps in understanding what the data presented actually means. For example, advocates had done questionnaires with "tons of questions" and they "felt rushed". What does this mean? Did the authors probe during the questionnaires regarding these responses to expand the answer--what they meant by their response? In line 21-23, there is not further information of examples of important missed areas to "say what is on his or her mind." Given the number of questions asked, the section provides minimal useful information to connect the answers with the Guiding Questions.	Thank you for your feedback. In our call with the Key Informants, we engaged in a rich discussion regarding these caregivers' experiences. We have enhanced the two areas that you flagged for us as needing more information. Regarding the "tons of questions" and "felt rushed", we have updated the sentence with more details: "Both caregivers reported that they had completed numerous written questionnaires with "tons of questions," which overwhelmed them and became so granular that the caregivers felt they could not provide an accurate depiction of their experience and the issues that mattered most to them. Caregivers also felt that the way the assessments were administered "always felt rushed" in that they did not have time to reflect on the questions and often just indicated "their initial thoughts" or just "bubbled in an answer.'"

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				Regarding providing more details about the “say what is on your mind” comment, we have updated the sentence below: “To enhance the efficacy of detailed assessment tools, the caregivers suggested that any encounter or survey should start with a question to identify the patient or family member’s unique “biggest concern,” and surveys or questionnaires should ultimately empower the patient or family member to “say what is on his or her mind.” For example, one caregiver supported her mother while she took care of her stepfather. The mother’s biggest concern was learning how she can keep her husband at home until the end of his life; this concern was not otherwise a priority for the physician.”
31	Peer Reviewer #3	Findings	The providers appear to also be researchers, e.g., lines 45-48 where there is mention of "ceiling effects."	We have clarified that these were provider/researchers.
32	Peer Reviewer #3	Findings	Lines 49-52 read as subjective opinions/statements on unintentionally incentivizing actions detrimental to patient care (treating pain aggressively to bring down pain scores). An example from the informant or their citation of data here would help to support this statement.	We clarified their role in the Key Informants section of the methods: “The role of the Key Informants was to inform the conduct of the review.” We did not ask informants to cite data. We asked for their subjective opinions.
33	Peer Reviewer #3	Findings	Lines 54-55 again put out an issue, but there is no information or examples from the authors of statements why "assessment are often not completed" and "cannot capture a global assessment of the patients actual clinical experience."	We clarified their role in the Key Informants section of the methods: “The role of the Key Informants was to inform the conduct of the review.” We did not ask informants to cite data. We asked for their subjective opinions.
34	Peer Reviewer #3	Findings	Results of the Literature Search and Supplemental Searches. Table 2 was useful and comprehensive. On results in lines 43-44 for the Spiritual, Religious, and Existential Domain, the authors indicate that websites were searched and no tools identified. Given though that they indicate "web searches" were done up to June 2010, it is unclear while tools such as the FICA Spiritual History (George Washington Institute for Spirituality and Health), the Hope Questions for Spiritual Assessment (Anandarajah G, Hight E. Spirituality and medical practice: using the HOPE questions as a practical tool for spiritual assessment (Am Fam Physician. 2001;63(1):87), the Functional Assessment of Chronic Illness Therapy -Spiritual Well-Being (FACIT-Sp) tool and the Spiritual Well-Being Scale, etc., were not identified. The web search may not have been specific to the literature review, but the results suggests that there are no new tools. A web search found articles on tools for spiritual assessment that	We have clarified the definition of assessment tool to be more clear about why FICA was not eligible for inclusion: “An instrument (generally a scale, questionnaire or survey) completed by or with patients or families that has been psychometrically evaluated and is used to collect data at the individual patient level.” The methodology of the review was based on use of systematic reviews and we did not include consensus reports. We have clarified in the methods that only tools developed for or evaluated in palliative care populations were included. We have added to the limitations, “Few studies have assessed spirituality tools in palliative care populations.

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			included palliative populations--some by CM Puchalski that describes the National Consensus Project prc.coh.org/pdf/EvalFICA.pdf	Tools including the Functional Assessment of Chronic Illness Therapy- Spirituality (FACIT-Sp) tool, the Spiritual Well-Being Scale, and the Koenig Religious Coping Index were therefore not included in this report, but may be useful in palliative care research.” The web searches were done after 2010 (the systematic review covered literature up to 2010).
35	Peer Reviewer #3	Findings	Pages 8-22. In the results of individual domains, the authors require the reader to rview the appendices. This may be due to page limits but there is very little information provided. For examples, lines 53-56, the authors note a supplemental search identified 25 tools. There is no other information on what the tools are or what the supplemental search findings mean. To see this information, the reader has to go to Appendix J, Evidence Table 1.	We appreciate this comment. We balanced the need for a succinct technical brief that is usable for most readers with more detail in appendices for those readers who wish to have these details.
36	Peer Reviewer #3	Findings	For each domain section, the results were compared to the Guiding Questions. In several of the paragraphs, some of the questions were not addressed (as commented in c. Guiding Questions). If a Question or subpart do not have information, then that should be stated for all sections in order to integrate the data and balance the information with the targeted questions in which the report was to address.	We have included a section at the end of the methods to be clearer how Guiding Questions were addressed: “Data Presentation: We developed evidence tables based on the domains and assessment tool contexts, settings, and populations. To address the Guiding Questions, we performed the following tasks: <ul style="list-style-type: none"> • Guiding Question 1: we catalogued and compiled tool characteristics by domain • Guiding Question 2: we described the current state of research for tools in each domain • Guiding Question 3: we catalogued the current state of research on use of the tools for evaluation of interventions, clinical care, and quality measurement (quality indicators) • Guiding Question 4: we provided a summation of relevant issues and gaps”
37	Peer Reviewer #3	Findings	Page 14 Ethical and Legal Domain. This authors completed the review appropriately. But the question remains if palliative care providers would be the correct individuals to use tools in this area. It would seem that legal experts, social workers(?), ethicists would be using these tools. What was anticipated, but missing, was at least web information or reviews related	Thank you. We have clarified the definition of assessment tools: “An instrument (generally a scale, questionnaire or survey) completed by or with patients or families that has been psychometrically evaluated and is used to collect data at the individual patient level.” The POLST/MOLST, advance directives, and decision aids do not meet this

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			to the POLST/MOLST paradigm, advance directive tools/decision aids, etc. Given that "care planning" was descriptive in background as part of this domain, it seemed questionable if data were missing.	definition of assessment tools.
38	Peer Reviewer #3	Summary and Implications	The authors provide a discussion of the important issues for this Technical Brief. Some unexpected findings are noted. For example, on page 24, lines 20-23, the issue of communication is identified as a need area and resulted in ancillary website searches on communication. It seemed as if this is area is part of Domain 1 (which lists communication)--so it is unclear from the text in the Report why this area was not more systematically evaluated in the full review.	We have reorganized the methods to more explicitly state that if we did not identify a systematic review on a topic of interest (e.g., for communication), we searched ancillary websites for the topic of interest.
39	Peer Reviewer #3	Summary and Implications	Lines 45-49, again, because there was no expert in spiritual domains used, statements by Key Informants are questionable and should be identified as a possible limitation of the study.	Thank you. Our key informants had significant expertise in spiritual domains and in palliative care assessment tools overall. The key informants are named in the final report.
40	Peer Reviewer #3	Next Steps	Important issues are summarized and recommendations made. these are concise and based on earlier section information.	Thank you for your comment.
41	Peer Reviewer #3	Clarity and Usability	The report was heavy on appendices and the reader checking these data to understand general statements made in the report. This was cumbersome. The methods assume that palliative care personnel would be using tools in many of the domains---however, as in the legal/ethical domain, psychiatric domain, or spiritual domain, who uses what tools may be dependent on the team member--or access to consultants with expertise in this area. Pain assessment tools exist but am not clear if the Report is recommending that there should be pain tools for 'serious illness', etc. etc.	We appreciate this comment. We balanced the need for a succinct technical brief that is usable for most readers with more detail in appendices for those readers who wish to have these details. We do not state in the methods that palliative care personnel would be using these tools or recommend that there should be pain tools for "serious illness". We have expanded the definition of assessment tools in the report to make this clearer.
42	Peer Reviewer #3	Clarity and Usability	The Report indicates at several points that it is to inform policy makers. It is not addressed what policy implications this report has.	The Technical Brief is not oriented to a particular audience; these are standard introductory comments for these reports. The goals of the Technical Brief are to provide an early objective description of the state of the science, a potential framework for assessing the applications and implications of the intervention, a description (not an evaluation) of ongoing research, and information on future research needs. This report does not have policy implications.
43	Peer Reviewer #4	General Comments	Page 8 - Domain 2: Physical - First line refers to National Consensus Statement. This should be changed to Guidelines.	Thank you for your comment, this has been changed in the text
44	Peer Reviewer #4	General Comments	Page 11 - Domain 5: Spiritual... - Why is the FACIT tool not included?	We have clarified in the methods that only tools developed for or evaluated in palliative care populations were

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				included. We have added to the limitations, "Few studies have assessed spirituality tools in palliative care populations. Tools including the Functional Assessment of Chronic Illness Therapy- Spirituality (FACIT-Sp) tool, the Spiritual Well-Being Scale, and the Koenig Religious Coping Index were therefore not included in this report, but may be useful in palliative care research."
45	Peer Reviewer #4	General Comments	Page 14 - Domain 7: Care at the End of Life. This content is all on Bereavement and doesn't address the issues of care at the end of life.	We have clarified in Table 1 and in this section that for the purpose of organizing the tools into domains, we included only bereavement tools in this section.
46	Peer Reviewer #4	General Comments	Page 19 - Table is titled.."QOL Tools" - Why are the MSAS and Condensed MSAS here? They are not QOL tools.	ESAS, MSAS cross National Consensus Project domains, and so they are included in the multidimensional section. We have clarified, "We included tools developed for or evaluated in palliative care populations in the domains and subdomains in Table 1, and added a category for multidimensional tools that cross domains." We recognize that there are many definitions of QOL – we used a broad characterization as used in the Albers et al. review: .."which may include areas such as physical health and functional status, mental health, social and role function, and physical and psychological symptoms..."
47	Peer Reviewer #4	General Comments	Table 8 & Table 9 are confusing: (pages 20-21) some tools are not QOL measures (such as "Quality of Dying"). Table 9 is titled "patient experiences" but several tools are for family caregivers.	We have removed QODD from Table 8. Table 9 is lists tools reporting patient experience, but most of these tools are for caregivers to report after the patient's death. The column "population" notes the target for completing the tool.
48	Key Informant #5	General Comments	What is this Technical Brief trying to accomplish?	We hope the clarifications raised by other reviewers and in your points below has helped to clarify this point.
49	Key Informant #5	General Comments	p 2 of 144 "The information in this report is intended to help healthcare decision-makers . . ." From the Guidelines for Reviewing Technical Briefs: "The potential audience includes early adopting clinicians, patients, payers, policy makers, and researchers."	The Technical Brief is not oriented to a particular audience; these are standard introductory comments for these reports. The goals of the Technical Brief are to provide an early objective description of the state of the science, a potential framework for assessing the applications and implications of the intervention, a description (not an evaluation) of ongoing research, and information on future research needs.
50	Key Informant #5	General Comments	Comment: This Technical Brief seems heavily aimed at researchers. As a clinician, I would have a hard time using it	The Technical Brief is not oriented to a particular audience; these are standard introductory comments for these

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			to decide which tools to use in a clinical practice and even more difficulty identifying quality indicators for my practice. As a patient or caregiver, I don't see how I would use this Technical Brief. Which leads back to defining the purpose of the Technical Brief and the intended audience. This is a well done Technical Brief for researchers. It has limited to no value for patients, caregivers, and most clinicians.	reports. The goals of the Technical Brief are to provide an early objective description of the state of the science, a potential framework for assessing the applications and implications of the intervention, a description (not an evaluation) of ongoing research, and information on future research needs.
51	Key Informant #5	General Comments	Suggestion: Review all references in the brief to the purpose, aim, or intention and be clear about it.	Thank you for your comment, and we have reviewed the references.
52	Key Informant #5	Background	: p 9 of 144, line 52 "This poses two challenges for researchers and policy makers . . ." This statement seems to confirm my opinion that this Technical Brief is aimed at researchers.	The Technical Brief is not oriented to a particular audience; these are standard introductory comments for these reports. The goals of the Technical Brief are to provide an early objective description of the state of the science, a potential framework for assessing the applications and implications of the intervention, a description (not an evaluation) of ongoing research, and information on future research needs.
53	Key Informant #5	Guiding Questions	Guiding questions are clear for researchers.	Thank you for your comment.
54	Key Informant #5	Methods	Methods are clear for researchers.	Thank you for your comment.
55	Key Informant #5	Findings	Findings are clearly identified for researchers.	Thank you for your comment.
56	Key Informant #5	Summary and Implications	This section ties together previous information.	Thank you for your comment.
57	Key Informant #5	Next Steps	Areas for further research are specific.	Thank you for your comment.
58	Key Informant #5	Clarity and Usability	Report is well structured and organized for researchers. Limited to no useability for patients, caregivers, and most clinicians.	Same as #49
59	Key Informant #5	Clarity and Usability	P 36 of 144 lines 14-23 As stated in the report, it is interesting that so few tools evaluate for responsiveness. While the report mentions this fact, there should be a specific, direct recommendation related to this issue in Next Steps.	We have added to the limitations section: "Although few tools had reported information on responsiveness, the primary focus of articles identified was on usability, reliability and validity. More detailed literature searches for each tool would be needed to determine evidence for responsiveness".
60	Key Informant #5	Clarity and Usability	Appendix C The Domains are the framework for this brief. Expand the description of each Domain here using the source document. The few "e.g.s" are not sufficient.	This Appendix provides the information that we used for the key informant interviews, so we cannot change it.

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61	Peer Reviewer #6	General Comments	This is a thorough review of assessment tools available to evaluate palliative care services.	Thank you for your comment.
62	Peer Reviewer #6	General Comments	As the authors note - the challenge is that few of these tools have been used in clinical practice or for quality indicators.	Thank you for your comment.
63	Peer Reviewer #6	General Comments	Main issue noted below is distinguishing symptom versus QOL measures.	ESAS, MSAS cross National Consensus Project domains, and so they are included in the multidimensional section. We have clarified, "We included tools developed for or evaluated in palliative care populations in the domains and subdomains in Table 1, and added a category for multidimensional tools that cross domains." We recognize that there are many definitions of QOL – we used a broad characterization as used in the Albers et al. review: .."which may include areas such as physical health and functional status, mental health, social and role function, and physical and psychological symptoms..."
64	Peer Reviewer #6	General Comments	The conclusions are recommendations for future research are well written and appropriate.	Thank you for your comment.
65	Peer Reviewer #6	Background	While I understand why the others needed to use some guideline on which to base their review - i dont know how much the NCP guidelines are really used and if they have significant utility. I agree that they are a comprehensive list of palliative care practice targets but i just do not see them referenced or referred to much in the literature, at palliative care national meetings, etc.	We appreciate your concern. With the guidance of the Key Informants, we chose to use the NCP guidelines as they have been used for multiple previous reviews of assessment tools that this review built on, and have added this to the introduction – "...given their use for prior reviews of assessment tools..."
66	Peer Reviewer #6	Background		
67	Peer Reviewer #6	Guiding Questions	well written	Thank you for your comment.
68	Peer Reviewer #6	Methods	clear and well described	Thank you for your comment.
69	Peer Reviewer #6	Findings	Rationale for focusing only on dyspnea and pain was not entirely clear to me. Understand that there are many, many physical assessment tools but palliative care studies have used these as outcome measures and many clinical sites are recommended standard use of tools such as ESAS or MSAS to screen for palliative care needs and as outcomes so a summary of the most commonly used tools may be helpful.	We have clarified this section: "We summarized assessment tools for the three key subdomains that were addressed in prior reviews: dyspnea, pain, and fatigue. These and other physical symptoms are also addressed in multidimensional tools for quality of life and patient experience." ESAS, MSAS cross National Consensus Project domains, which is why they are included in the multidimensional section.
70	Peer Reviewer #6	Findings	For QOL, unclear why only the EORTC with 2 subscales were included and why for FACT only FACT-PC was included whereas for EORTC it was esophageal and gastric.	We have added a line on inclusion criteria in data collection to clarify that we included tools tested in palliative care populations: "We included tools developed for or evaluated in palliative care populations in the domains and subdomains in Table 1..."
71	Peer Reviewer #6	Findings	Table 8 also includes a number of tools which are more about symptoms than QOL - ESAS, MSAS so to my point above those would be more appropriate as symptom measures	ESAS, MSAS cross National Consensus Project domains, which is why they are included in the multidimensional section. We have clarified, "We included tools developed

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			rather than QOL tools. I think the placement of symptom measures in QOL section is a bit unclear as these are different constructs.	for or evaluated in palliative care populations in the domains and subdomains in Table 1, and added a category for multidimensional tools that cross domains." We recognize that there are many definitions of QOL – we used a broad characterization as used in the Albers et al. review: .."which may include areas such as physical health and functional status, mental health, social and role function, and physical and psychological symptoms..."
72	Peer Reviewer #6	Next Steps	agree	Thank you for your comment.
73	Peer Reviewer #6	Clarity and Usability	my main issue is with the difference between symptom measures and QOL. I dont know anyone in the field who would consider ESAS a QOL measure....i think this needs to be addressed.	Will insert the same response as above on the definition of QOL.
74	Key Informant #7	General Comments	Strengths: -Standardized methodology -The lack of responsiveness is an important concern - a bigger concern is the lack of funding that is devoted to measure development that allows for this to occur. -The task was quite was substantial – cudos for getting this done in a timely fashion.	Thank you for your comment.
75	Key Informant #7	General Comments	Concerns: "Assessment tools" - I found this very confusing term to use - In the clinical context, I would not think of many of these tools as an clinical assessment tools. Perhaps, they are using it in a broader context, but I feel this lack of precision of the intended use of the tool really determines what standards that we should hold a "tool" too (e.g., for an excellent discussion of this see Solberg J Qual Imp 1997). For example, a measure for public reporting or accountability should be held to higher standards. I feel the use of this term and not being clear on the intended use of the measure clouds the interpretation of the report. It is a substantial concern to this report.	We have clarified the definition of assessment tool to be clear that it does not address intended use for public reporting or accountability: "...data collection instrument (generally a scale, questionnaire or survey) that has been psychometrically evaluated and is completed by or with patients or caregivers, that collects data at the individual patient or caregiver level.
76	Key Informant #7	General Comments	Concerns: The proposed definition of an assessment tool, ignores the important role of the family and those who provide care for the dying patient. The Medicare Hospice Benefit is based on family or close friend providing the care with the support and guidance of a hospice. Same is true for dementia, cancer, etc.	The definition includes caregivers: "...completed by or with patients or caregivers, that collects data at the individual patient or caregiver level."
77	Key Informant #7	General Comments	Concerns: Instruments evolve over time - perhaps, things are not published - but based on working in this field - there in	The purpose of this review was to provide a broad overview of the tools that exist, not to describe the tool development process. We did not conclude that there were

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			<p>accuracies in this report that raise concerns. The author makes a conclusion there is no tool available for the legal aspects. FATE, a multi-item survey in the VA had items that asked about legal help that we tested with our AHRQ funded revision of the Family Evaluation of Hospice Care Survey. Those items were dropped because it was low frequency of it being a concern. The authors should consider contacting the principle author to review their findings. I have done this other instrument reviews. If they have done this, they would have found they needed to go to technical appendix in JAMA that validation information in 2004 and that the Family Evaluation of Hospice Care survey underwent further testing that was unpublished in medical literature, but available on the NHPCO web site. We created an overall composite which is the part of the endorsement of the NQF for the instrument which was mainly in response to not wanting to submit so many composites in response to NQF decision not to endorse “surveys” but at the time of submission requiring a submission for each composite. Similarly, we did test some cultural items for the revision of the FEHC as well the development of CAHPS Hospice survey, but they were dropped with low frequency of being concerned and the need to have a survey with reasonable length.</p>	<p>no tools for legal aspects but state that there were few tools: 1st paragraph of discussion: “.other domains (Spiritual, Religious, and Existential; Cultural; and Ethical and Legal) had few tools.” We appreciate this very valuable additional information you have provided and we have added this issue to the discussion on culture: “Future research is also needed to determine how this domain could be included in multidimensional tools, although researchers may find this challenging due to a low percentage of patients endorsing cultural items.”</p>
78	Key Informant #7	Guiding Questions	It would be helpful to frame the tools based on the intended use (clinical assessment, QI, Research, Accountability)	The intended use of the tools was not generally described in the literature, so we included a section on how the tools were actually used. We have added a section on data presentation to make clearer where this was included, which states: “Guiding Question 3: we catalogued the current state of research on use of the tools for evaluation of interventions, clinical care, and quality measurement (quality indicators).”
79	Key Informant #7	Methods	Should have contacted primary authors of tools to get additional information Should have review information readily available on NQF web site.	Thank you. The purpose of this review was to provide a broad overview of the tools, rather than an extensive search of the literature for each tool. We have added to the limitations, “Included systematic reviews may have missed some eligible tools or studies evaluating some properties of these tools.”
80	Key Informant #7	Findings	Table 3 – it is not clear why you are reporting the internal consistency of a single item – there should be a footnote that notes that it is N/A	This was an error in editing the report and has now been fixed.
81	Key Informant #7	Findings	Early on they need to say how they handled multi-item composites - which may cover multiple domains, in separate tables . For example, CAHPS Hospice has items that assess unmet needs for spirituality.	We have added to the methods – data collection – “We included tools developed for or evaluated in palliative care populations in the domains and subdomains in Table 1, and added a category for multidimensional tools that cross

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				domains.”
82	Key Informant #7	Findings	Without spending a lot of time, there are concerns the accuracy of the information – e.g, the QODD or composites has been tested in published interventions and I believe that time of administration is known.	The purpose of this review was to provide a broad overview of the tools, rather than an extensive search of the literature for each tool. In the discussion, we have revised the statement under applications of tools to read, “Additional analysis of the responsiveness and appropriateness of tools, particularly across diseases and populations, would help determine which patient and caregiver assessment tools are most useful in the evaluation of different types of palliative care interventions.” We have added to the limitations, “Included systematic reviews may have missed some eligible tools or studies evaluating some properties of these tools.” And “Although few tools had reported information on responsiveness, the primary focus of articles identified was on usability, reliability and validity. More detailed literature searches for each tool would be needed to determine evidence for responsiveness.”
83	Key Informant #7	Findings	The POS – has several derivative instruments that is available based on google search on King’s web site that should be included.	We have added to the limitations, “Finally, some tools noted in the review also have multiple versions that were not always noted in our sources, and future use of these tools should search for different versions that might be more appropriate.”
84	Key Informant #7	Findings	All the information that they state is not present in articles that describe the use of FEHC and not the psychometric properties of the instrument. All of that information is an NQF endorsement and readily available based on web search.	We limited the information on psychometric properties to the published literature.
85	Key Informant #7	Findings	The tables should state the intended use of the tools	This information was available for very few of the tools, so we did not include it in our tables.
86	Key Informant #7	Findings	Page 22, the report talk about the use of measurement tools – I think the better framework is clinical assessment tool, quality indicator, and evaluation of interventions	Thank you. We include this at the end of the introduction: “... we also summarized research on the use of palliative care assessment tools for three applications in palliative care: clinical practice, quality indicators, and evaluation of interventions in studies.”
87	Key Informant #7	Findings	Through out, the report they use the term “few to no or few to none.” to refer to the number of measurement tools. There is quite a difference between “none” and one, if that one instrument is a good measurement tool as well as widely used.	We have reviewed the report and edited to change to “few” only or “none” only wherever we used this term.
88	Key Informant #7	Findings	Note I think this review should discuss what is mandated in the MDS and OASIS tool. That is important policy leverage point.	Thank you for this comment. We have added more detail in data collection on the inclusion criteria to why we did not include these tools clearer – “We included tools developed for or evaluated in palliative care populations...”

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89	Key Informant #7	Summary and Implications	Agree with recommendations of need for responsiveness	Thank you for your comment.
90	Key Informant #7	Summary and Implications	Inaccuracies in report raise important concerns	Thank you for bringing these to our attention. We have addressed your concerns about our findings in previous comments.
91	Key Informant #7	Next Steps	These need to be strengthened	We have made edits as suggested by other reviewers.
92	Key Informant #7	Clarity and Usability	My main concern is organizing or limiting the report by the intended use of the measurement tool	We did not organize or limit the report by intended use. We have added more detail in data collection on the inclusion criteria to make this clearer – “We included tools developed for or evaluated in palliative care populations in the domains and subdomains in Table 1...” and have removed content on intended use of the tools from the discussion.
93	Peer Reviewer #8	General Comments	Very well written report on unidimensional and multidimensional tools for palliative care evaluations. It is well organized and the tables are very helpful	Thank you for your comment.
94	Key Informant #8	Background	Well written. No concerns	Thank you for your comment.
95	Key Informant #8	Guiding Questions	No concern	Thank you for your comment.
96	Key Informant #8	Methods	There are 2 elements that need to be addressed in this document: 1. Caregiver/ family tools are available for cancer and palliative care and probably also for other conditions in pall care (See Tanco K et al for recent systematic review in cancer). The caregiver/ family is the source of most pall care at home and their evaluation is considered a major component of pall care delivery. For completeness it would be important to present some tools available. 2. Measures of integration: There are no standard tools but a measure of integration between palliative care and the primary care team is considered a major component of care. There have been systematic reviews and Delphi studies published in this important area (see Hui D et al for both). Some discussion of measure of integration and the need to develop more structured and validated tools for program evaluation would be needed	1. Thank you for this comment. We have clarified in Table 1 that the Social domain is caregiver tools (this is Domain 4). 2. We have clarified the definition of assessment tools to be clear why we did not include measures of integration: “An instrument (generally a scale, questionnaire or survey) completed by or with patients or families that has been psychometrically evaluated and is used to collect data at the individual patient level.”
97	Key Informant #8	Summary and Implications	It is very well written	Thank you for your comment
98	Peer Reviewer #9	General Comments	This work is important, timely, comprehensive and will be a great service to the growing knowledge base about palliative care.	Thank you for your comment
99	Peer Reviewer #9	Background	The use of the National Consensus Guidelines (lines 25-33 upfront is very helpful for setting context. This section thoroughly describes the clinical problem and makes a case for why assessment tools are critically needed. The definition	Thank you for your comment

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			of terms (lines 43-58 is essential.	
100	Peer Reviewer #9	Guiding Questions	This section does explain changes--e.g. the inclusion of a section for multidimensional tools.	Thank you for your comment
101	Peer Reviewer #9	Methods	The Methods are clear, concise and easy to follow. The methods utilized for this technical brief are comprehensive. The appendices are extremely helpful and easy to use.	Thank you for your comment
102	Peer Reviewer #9	Findings	This section reflects the view I had of palliative care assessment but provides data to substantiate the gaps. The evidence map(s) in the forms of appendices are very clear.	Thank you for your comment
103	Peer Reviewer #9	Summary and Implications	The Discussion accurately illuminates the strengths and limitations of the current state of assessment science in palliative care. This provides the rationale for needed tool development.	Thank you for your comment
104	Peer Reviewer #9	Next Steps	This section is very clear and representative of what I again have experienced anecdotally--this is data driven.	Thank you for your comment
105	Peer Reviewer #9	Clarity and Usability	Absolutely yes to all three questions. Very usable. This tool will be very helpful for the growth and development of the field.	Thank you for your comment
106	Key Informant #10	General Comments	This is a very thorough, well written and detailed report. The description of the methods are clear and the conclusions direct and straightforward. The authors did an excellent job of organizing, synthesizing, summarizing, and presenting a tremendous amount of data. The use of the NCP guidelines is a useful framework, though as the authors write there are some domains that are missing. It would be helpful if the authors provide more background about the NCP guidelines, particularly on the types of topics/outcomes/assessments within each domain and a list of key areas not covered. The input from caregivers was very interesting- would have been great to include more caregivers for additional input. The conclusions do not relate back to caregiver input but could and should.	<p>We have clarified in Table 1 what subdomains were included, and in the methods, "We included tools developed for or evaluated in palliative care populations in the domains and subdomains in Table 1, and added a category for multidimensional tools that cross domains."</p> <p>We have clarified in the methods in the key informants section, "The role of the Key Informants was to inform the conduct of the review." In the discussion, under "Applications of Assessment Tools", we have added, "Consensus recommendations should also include broader input from patient and caregiver perspectives ."</p>
107	Key Informant #10	Background	Clear and well written. Page 9pdf/pg 1 report, lines 39-41: would help to clarify and explain in more detail about quality indicator. Not clear from the description.	We have given a detailed description in definitions: " <u>Quality indicator</u> : A population-based measure that enables users to quantify the quality of a specific aspect of care by comparing it to evidence-based criteria. ³ Indicators require the identification of two groups: (1) the numerator—patients whose care meets the indicator criteria (e.g., those who are asked about their pain), and (2) the denominator—those who are eligible for the indicator, or the population of focus (e.g., all patients with a serious illness). When quality indicators include patient- or caregiver-reported data, they require the use of assessment tools."
108	Key Informant #10	Background	Pg 10pdf/pg 2 report, lines 45-48: repeat assessments of	Thank you – this report is about assessment tools, not

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			pain provide information about quality of care. Does that make the individual pain assessments quality of care or the analysis of repeated pain assessments result in a quality measure. Perhaps a small point, but seems that the assessment is about pain that can be analyzed as a quality outcome rather than as a quality outcome per se	quality measures. We have clarified the definition of assessment tool: "An instrument (generally a scale, questionnaire or survey) completed by or with patients or families that has been psychometrically evaluated and is used to collect data at the individual patient level.
109	Key Informant #10	Methods	Page 15 pdf/pg 7 report, Table 2: column headings could be more descriptive/detailed to make it easier for the reader to understand.	We have reviewed the column headings for level of detail.
110	Key Informant #10	Methods	Page 16 pdf/pg 8 report, lines 19-23: Consider giving examples of what types of issues would be included in Domain 1 that patients and caregivers would report on. The title Structure and Processes doesn't immediately bring to mind pt/caregiver outcomes/reports.	Thank you – we have clarified in Table 1 that we included continuity and communication, and in the methods, "We included tools developed for or evaluated in palliative care populations in the domains and subdomains in Table 1, and added a category for multidimensional tools that cross domains."
111	Key Informant #10	Findings	Generally very clearly presented. They cover a lot of information in a brief space complemented nicely by the tables in the text and the appendices.	Thank you for your comment
112	Key Informant #10	Findings	Page 22pdf/pg 14 report, line 19: where you write (not patients) you can add, "as expected only for caregivers."	Thank you for your comment; on review, we felt the current wording was clear.
113	Key Informant #10	Findings	Lines 35-38: provide examples of the legal/ethical domain that patients/caregivers would report	We have clarified in Table 1 that we included tools about care planning, and in the methods, "We included tools developed for or evaluated in palliative care populations in the domains and subdomains in Table 1, and added a category for multidimensional tools that cross domains."
114	Key Informant #10	Summary and Implications	The summary is very helpful i providing an overview of key findings. It would be helpful to provide additional interpretation of the findings: where are there good measures, which would be recommended to use. Seems that responsiveness is an area not well studied but essential for research and quality assessment. That point is not highlighted in the report.	We have added to next steps, "Other organizations may use the survey of tools in this report to provide more specific recommendations for tools; consensus work to recommend tools would be helpful for researchers in palliative care." We have now highlighted responsiveness in next steps: "Additional analysis of the responsiveness and appropriateness of tools, particularly across diseases and populations, would help determine which patient and caregiver assessment tools are most useful in the evaluation of different types of palliative care interventions."
115	Key Informant #10	Summary and Implications	The authors correctly highlight the different uses of these outcome measures. The summary could better delineate how the current state of assessment addresses these different uses.	We have added to next steps, "Other organizations may use the survey of tools in this report to provide more specific recommendations for tools; consensus work to recommend tools would be helpful, particularly for future evaluations of interventions."
116	Key Informant #10	Summary and Implications	Page 32pdf/pg 24 report, lines 16-17: can delete the word "with" just before the colon and add "by domain"	Thank you, we have made the change to the text

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117	Key Informant #10	Next Steps	I like the bullet point approach and description of specific tasks to be done. This approach and the level of detail in the systematic review section works very well. In the other two areas: evaluation and application more detail about the specific types of studies and research to be done would be helpful to guide the reader and the field. The authors have tremendous experience and expertise to provide additional guidance to researchers- what types of studies, how would they be done, what specific questions need to be asked. If this information is too detailed for the report, consider another appendix to provide more detailed information.	We have added to next steps, "Other organizations may use the survey of tools in this report to provide more specific recommendations for tools; consensus work to recommend tools would be helpful for researchers in palliative care.
118	Key Informant #10	Clarity and Usability	Table 10a: in the column inclusion criteria there are typos in a few words that are hyphenated but don't need to be: process, de-fined, numera-tor	We have corrected these errors in the Appendices
119	Key Informant #10	Clarity and Usability	It may be beyond the scope of this report, but would be very helpful if there was some guidance as to which measures to use. Right now the only metric to guide usage is how often some assessments have been used and the details about how the assessments were validated and evaluated. The authors could provide guidance to readers about how to interpret the tables that would help them choose among assessments.	We have added to next steps, "Other organizations may use the survey of tools in this report to provide more specific recommendations for tools; consensus work to recommend tools would be helpful, particularly for future evaluations of interventions."
120	Key Informant #11	General Comments	Overall this is an outstanding report. It is very clearly written, comprehensive and well organized. One area that could be improved upon is a more specific delineation of the population of seriously ill patients being addressed. Palliative Care is a field that applies across the life spectrum. The report does not discuss whether the review is inclusive of assessment tools for seriously ill children. If inclusive of children then, the review should specify this across sections and findings in Pediatrics should be address. If not inclusive of children, then the review should specify this a priori so that there is no expectation of addressing this topic in the review.	We have added to the methods (end of data collection): "We included all age groups, populations, and settings." For each tool, we include a column on population. We have added to next steps, "A high-quality systematic review focusing on the use of tools in pediatrics would also be useful."
121	Key Informant #11	Background	Very well written and thorough	Thank you for your comment
122	Key Informant #11	Guiding Questions	Very clear	Thank you for your comment
123	Key Informant #11	Methods	Very clear except with regard to whether pediatric patients would be included.	Thank you for your comment
124	Key Informant #11	Findings	Very well presented	Thank you for your comment
125	Key Informant #11	Summary and Implications	Accurately reflects findings	Thank you for your comment
126	Key Informant #11	Next Steps	Well delineated	Thank you for your comment
127	Key Informant #11	Clarity and Usability	Extremely readable	Thank you for your comment

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128	Key Informant #12	General Comments	The document is thorough and generally well written. There are some inconsistencies in the table, even for the same instruments.	Thank you for your comment
129	Key Informant #12	Background	Overall, well done. I think the definitions could be a bit more clear. For example, does this review only include patient and family reported outcomes or would it also incorporate information from the electronic health record particularly about the processes of care such as discussions about advance care planning or implementing components of palliative care.	We have clarified the definition of assessment tool: "An instrument (generally a scale, questionnaire or survey) completed by or with patients or families that has been psychometrically evaluated and is used to collect data at the individual patient level."
130	Key Informant #12	Guiding Questions	Clear and concise.	Thank you for your comment
131	Key Informant #12	Methods	Complete and well done.	Thank you for your comment
132	Key Informant #12	Findings	There are some important inconsistencies across the tables. For example, for the QODD in table 8 is reported to have internal consistency and convergent validity – which is correct – while in table 9 the same instrument is reported as not having these features.	We removed the QODD from Table 8. (The review cited in Table 9 did not review these characteristics (which was what ND meant in the draft report. We have clarified the footnote for ND)).
133	Key Informant #12	Findings	<p>There are other instruments that assess patient-reported quality of palliative care that are not included in this review for unclear.</p> <p>2. Quality of communication:</p> <p>Engelberg RA, Downey L, Curtis JR. Psychometric characteristics of a quality of communication questionnaire assessing communication about end-of-life care. <i>Journal of Palliative Medicine</i> 2006; 9:1086-1098.</p> <p>Janssen D, Curtis JR, Au DH, Spruit MA, Downey L, Schols JMGA, Wouters EFM, Engelberg RA. Patient-clinician communication about end-of-life care for Dutch and US patients with COPD. <i>European Respiratory Journal</i> 2011;38:268-276</p> <p>Au DH, Udris EM, Engelberg RA, Diehr PH, Bryson CL, Reinke LF, Curtis JR. A randomized trial to improve communication about end-of-life care among patients with COPD. <i>Chest</i> 2012; 141:726-735.</p> <p>Curtis R, Back AL, Ford DW, Downey L, Shannon SE, Doorenbos AZ, Kross EK, Reinke LF, Feemster LC, Barbara Edlund B, Arnold RW, O'Connor K, Engelberg RA. Effect of communication skills training for residents and nurse practitioners on quality of communication with patients with serious illness: a randomized trial. <i>JAMA</i> 2013; 310:2271-</p>	<p>Thank you for your comment.</p> <p>The Engelberg tool is included under communication in the appendices.</p> <p>Our review focused on studies of psychometric properties of tools, which is why the Janssen, Au and Curtis articles were not included.</p> <p>The last Engelberg article was not included in the very comprehensive review of patient experience tools that we used for this review, that covered the year 2010. We have added to the limitations, "Included systematic reviews may not have included some potentially relevant tools."</p>

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			2281. 2. Quality of end-of-life care Engelberg RA, Downey L, Wenrich MD, Carline JD, Silvestra GA, Dotolo D, Nielsen EL Curtis JR. Measuring the quality of end-of-life care. Journal of Pain and Symptom Management 2010; 39:951-971.	
134	Key Informant #12	Summary and Implications	Well done and concise. I think it would be helpful to provide a bit more details summary across the different domains.	We have provided additional detail in places as recommended by other reviewers.
135	Key Informant #12	Next Steps	Well done and concise. Perhaps consider including a table of future research needed that provides some more detail.	We have provided additional detail in places as recommended by other reviewers. .
136	Key Informant #12	Clarity and Usability	The report is well structured and organized. The conclusions clearly will inform future research, but there are some important inconsistencies and missing measures that would be good to add. I have included the ones I know of, but the missing items raise questions about what else might be missing.	We have added in comments on specific measures as you have noted here and as noted from other reviewers in the limitations section.
137	Peer Reviewer #13		SEE PUBLIC COMMENTS	
138	Key Informant #14	General Comments	This report summarizes and synthesizes the key literature on palliative care assessment tools that can serve as a 'bible' of the current state of the science and lay the foundation for future research. Recognizing the progress but also the gaps is critical first step for progress to be made. Though I can't recall whether it was mentioned in Key Informant discussion it now seems that other areas that are missing besides communication are decision-making and preparedness. These are key areas of focus in palliative care that are important in clinical care, quality indicators and evaluating effectiveness of interventions. There are a few tools but much more work is needed. Not sure which domain should include; probably ethical legal. Having said this though brings to mind that the NCP guideline domains are very acute care, end-of-life focused and preparation and early palliative care are poorly embedded in the guidelines. Hence why this was not a focus of the assessment tools.	We have added to the limitations: "Using the National Consensus Project Guidelines as a framework for the domains and limiting to tools evaluated in palliative care populations excluded some types of tools that may be relevant in some applications in palliative care populations."
139	Key Informant #14	Background	The report clearly and succinctly identifies and recognizes focused efforts on assessing a limited number of the most common domains of comprehensive palliative care practice. Historical foundations are identified and all pertinent prior work/reviews seem to be acknowledged.	Thank you for your comment.
140	Key Informant #14	Guiding Questions	The guiding questions are relevant and comprehensive. One concern is that although the search strategy and inclusion	We have added to the methods – data collection – "We included tools developed for or evaluated in palliative care

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			criteria are described I had trouble locating why tools would have been excluded. I suspect others may have this question and will argue that certain tools are 'missing' from the review if this isn't more prominent.	populations."
141	Key Informant #14	Methods	<p>The systematic review process was clearly delineated and seemed to be exhaustive. The complexity of identifying literature that addressed clinical, quality, and research measurement is a challenge; nevertheless the authors were thorough and creative in identifying key documents across these domains. The use of the National Consensus Guidelines Domains to guide the review was appropriate and intuitive structure for the reader to gain the most value from the document.</p> <p>As stated above a clearer description of what was not included and why is important (eg there are many more caregiver tools than those listed in the social domain and it is not clear to me why they were omitted..Montgomery-Borgatta Caregiver Burden Scale.</p>	<p>We have expanded the discussion section on caregiver tools to note why these were not included and need for further testing in palliative care populations. The MBCBS, like most caregiver tools, was excluded because it was not tested in palliative care populations.</p> <p>We have also added to the methods –under data collection – “We included tools developed for or evaluated in palliative care populations.”</p>
142	Key Informant #14	Findings	<p>The strengths and weaknesses of the existing categories / domains of patient/caregiver experience tools have been identified as well as the domains where tools are mostly non-existent.</p> <p>P. 23 uses term that I've not seen before: 'conjugally bereaved elders'.</p> <p>p. 55 typo in heading clutre instead of culture</p>	Thank you for your comment. We have rephrased as “bereaved spouses”.
143	Key Informant #14	Summary and Implications	The creation of this report has done a great service to the field, including for clinicians, researchers, and health services administrators and policy makers as it recognizes the areas which have valid and reliable measures that are ready for practice and dissemination and those that are not yet there.	Thank you for your comment
144	Key Informant #14	Next Steps	Clear, concise, and prescriptive. Seems like a good place for a researcher to start on instrument development.	Thank you for your comment
145	Key Informant #14	Next Steps	Not sure why PROMIS tools are not mentioned as to why not included. I know it wasn't developed specifically for pall care, but given the importance of PROMIS it seems like an omission to not mention the place of PROMIS in intervention evaluation at the very least.	<p>This report focuses on tools developed for/ tested in palliative care populations. We have added this to the limitations: “Using the National Consensus Project Guidelines as a framework for the domains and limiting to tools evaluated in palliative care populations excluded some types of tools that may be relevant in some applications in palliative care populations.”</p> <p>None of the evaluations of interventions used PROMIS.</p>
146	Key Informant #14	Clarity and Usability	The writing was very clear and made this complex topic very accessible. The evidence tables and summaries will make this very usable to clinicians, researchers, policy makers and administrators.	Thank you for your comment

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147	Public Comments #1 (Dr. Kim Kuebler)	Introduction	The focus of this document is to include the National Consensus Model - this content is primarily focused on end of life care - and Hospice. Palliative Care is symptom management from an interdisciplinary approach - to include the patient and family. There is a huge emphasis on end of life care and cancer. Palliative care has shifted backward and should be integrated into the management of chronic condition's - used to reduce symptom exacerbation and reduce hospitalization and disability.	We did not focus on end of life care and hospice. With the input of the key informants, we chose the palliative care definition of serious, advanced illness. We have added to the limitations, "We also recognize that other definitions of palliative care exist, and the tools covered in this report do not cover the full scope of potentially relevant populations."
148	Public Comments #1 (Dr. Kim Kuebler)	Methods	Should include literature searches on palliative practices outside of US and outside of end of life care	With the input of the key informants, we focused on the US, given that practices vary widely among countries. We did not limit to end of life care – the scope was palliative care, defined as serious, advanced illness.
149	Public Comments #1 (Dr. Kim Kuebler)	Results	End of life care is not necessarily palliative care - palliative care should be encouraged to be integrated earlier in the diagnosis of a chronic condition. There is no discussion or consideration to rehabilitation, literacy, Shared Decision Making, Self Management, Use of current guidelines to standardize the use of assessment tools Chronic conditions differ from cancer - the differentiation between chronic disease and malignancy has to be made	We did not limit to end of life care. With the input of the key informants, we used the National Consensus Project as the framework, which did not include these areas. We have added to the limitations, "Using the National Consensus Project Guidelines as a framework for the domains and limiting to tools evaluated in palliative care populations excluded some types of tools that may be relevant in some applications in palliative care populations. In each table, the population for the tool is listed to show which were tested for cancer and which for other diseases.
150	Public Comments #1 (Dr. Kim Kuebler)	Discussion	Structure of care from the National Consensus Model is missing important, timely and current information - the Chronic Care Model and the Transitions in Care Model should be included in palliative care - care outside of hospice and end of life is important to include. There is a multisymptom assessment tool- The Edmonton Symptom Assessment Tool, the Palliative Care Program in Edmonton Canada was the originator of the first clinical tools developed for Palliative Care - none of this is included Why are Pain and Dyspnea separated from all other symptoms - patients with chronic conditions and cancer have multiple concomitant symptoms Domain 4 - nothing on social determinants Quality of Life tools should include Activities of Daily Living - There is nothing on physical functioning and rehabilitation assessment	We did not limit to hospice and end of life care. With the input of the key informants, we used the National Consensus Project as the framework, which did not include these areas. We have added to the limitations, "Using the National Consensus Project Guidelines as a framework for the domains and limiting to tools evaluated in palliative care populations excluded some types of tools that may be relevant in some applications in palliative care populations. The ESAS tool is included along with multiple other tools that address many types of symptoms in the multidimensional - quality of life section, since it crosses domains. We have clarified for pain and dyspnea: "As described in the National Consensus Guidelines for Quality Palliative Care, physical symptom subdomains include numerous symptoms such as pain, shortness of breath, nausea, fatigue, anorexia, insomnia, restlessness, confusion, and constipation. We summarized assessment tools for the

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				<p>three key subdomains that were addressed in prior reviews: dyspnea, pain, and fatigue. These and other physical symptoms are also addressed in multidimensional tools for quality of life and patient experience.</p> <p>Domain 4: we did not identify any assessment tools on social determinants of health for palliative care populations. Quality of life tools do include physical functioning, as described in the definition in the beginning of this section: "quality of life (which may include areas such as physical health and functional status, mental health, social and role function, and physical and psychological symptoms)</p> <p>Rehabilitation assessment was not included in the NCP domains.</p>
151	Public Comments #1 (Dr. Kim Kuebler)	Appendices	Table D-4 of Appendix heading typo. Probably should state "culture" instead of "clutre" Line #3 of search strategy also begins with typo "ulture[mh]	Thank you, we have corrected the typographical errors
152	Public Comments #1 (Dr. Kim Kuebler)	General Comments	Palliative care is moving forward and not backward - the focus in this document is primarily on end of life care and issues - Palliative care should be integrated into the care and management of the patient and family at the onset of a chronic condition. This reduces the burden of symptoms and the precipitation of disease exacerbation's - which largely contribute to hospital admission (heart failure, COPD etc). Differentiate from malignancy and chronic conditions - they are not the same and the assessments differ Need to include AHRQ tools on shared decision making, self management, literacy, etc	With the input of the key informants, we used the National Consensus Project as the framework, which did not include these areas. We have added to the limitations, "Using the National Consensus Project Guidelines as a framework for the domains and limiting to tools evaluated in palliative care populations excluded some types of tools that may be relevant in some applications in palliative care populations.
153	Public Comments #2 (Christina Puchalski)	General Comments	Overall the report is very informative My additional comments on the spiritual domain is as follows: The definition of palliative care does not match other definitions such as the recent WHO pall care resolution. The later includes attention to suffering, psychosocial and spiritual as well as physical. I would recommend broadening that defintion.Attention to suffering is an important element of what palliative care professionals do. A key publication and body of work that is missing is the consensus report on IMproving the Quality of the SPiritual Domain of Palliative care Puchalski, Ferrell, Virani et al JPM 2009. In this report a concensus derived defintion of spirituality in palliative care is published and recommendations for implementing an interprofessional model of spiritual care. This report also has been cited by	<p>We appreciate that there are many definitions of palliative care – in consultation with our key informants, we chose to use a US-based definition from Dying in America. We did include the spiritual and psychosocial domains, as included in the National Consensus Project. We have added to the limitations, "We also recognize that other definitions of palliative care exist, and the tools covered in this report do not cover the full scope of potentially relevant populations."</p> <p>We have also clarified the definition of assessment tool to be clearer why FICA was not included: "An instrument (generally a scale, questionnaire or survey) completed by or with patients or families that has been psychometrically evaluated and is used to collect data at the individual</p>

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			<p>NQF and also IOM in its report on dying in america. There are additional tools that have been validated for spiritual assessment. One if the FICA tool which has been validated for cancer patient (Borneman et al, 2009 JPM) The other is the FACET-sp which is used for research, and the City of Hope Quality of life instrument--the spiritual domain. I have attached the WHO pall care resolution and the papers i mentioned to this document</p>	<p>patient level.”</p> <p>The methodology of the review was based on use of systematic reviews and we did not include consensus reports.</p> <p>We have clarified in the methods that only tools developed for or evaluated in palliative care populations were included.</p> <p>We have added to the limitations, “Few studies have assessed spirituality tools in palliative care populations. Tools including the Functional Assessment of Chronic Illness Therapy- Spirituality (FACIT-Sp) tool, the Spiritual Well-Being Scale, and the Koenig Religious Coping Index were therefore not included in this report, but may be useful in palliative care research.”</p>
154	Public Comments #3 (Altarum Institute)	General Comments	<p>The problem is that the report itself then adopts the framework of the National Consensus Project for Quality Palliative Care, which was a worthy project staffed by practitioners self-identified as providing palliative care. One might think that this works well, but it plainly does not.</p>	<p>With the input of the Key Informants, we used the National Consensus Project to define the scope. We have added to the limitations, “Using the National Consensus Project Guidelines as a framework for the domains and limiting to tools evaluated in palliative care populations excluded some types of tools that may be relevant in some applications in palliative care populations.</p>
155	Public Comments #3 (Altarum Institute)	General Comments	<p>This report probably does a good job on the limited scope it reports. But it should be titled something like “Assessment Tools for the Scope of Work Commonly Claimed by Palliative Care Practitioners.” Most of palliative care focuses on hospital patients and cancer, and the report seems generally adequate and appropriate for those settings. It does not deal with persons needing long-term supportive services, which is the most prevalent category of persons living with “serious advanced illness.”</p> <p>Consider the situation of a person living with moderate or severe dementia of the Alzheimer’s type. Is this a person who is a “patient with serious advanced illness?” Surely, the answer is yes. But the dimensions of “other symptoms” that are relevant to this person and his or her family include managing difficult behaviors without restraints (physical or pharmacological), avoiding contractures and pressure ulcers, limiting family burden, providing appropriate dental and podiatry care, and assuring reasonable hygiene. None of these are within the scope of this report.</p>	<p>Thank you for your comment on the title; we appreciate that definitions and the scope of palliative care vary. With the input of the Key Informants, we used the National Consensus Project to define the scope. We have added to the limitations, “Using the National Consensus Project Guidelines as a framework for the domains and limiting to tools evaluated in palliative care populations excluded some types of tools that may be relevant in some applications in palliative care populations. We also recognize that other definitions of palliative care exist, and the tools covered in this report do not cover the full scope of potentially relevant populations.”</p>

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			<p>Consider the situation of a person living with the adverse effects of serious alcohol use. In addition to many of the issues above, this person raises the issues of minimizing ongoing harm, providing supervision, enabling decision-making if possible – all not considered.</p> <p>And as a final example, consider the situation of a person who is simply experiencing the syndrome of frailty in advanced old age, with loss of muscle and weight and mild depression. Here, maintaining residence in the community, avoiding falls, assuring food and housing, minimizing loneliness, and sustaining caregivers are among the elements that come to the fore. Again, these are not within this report.</p>	
156	Public Comments #3 (Altarum Institute)	General Comments	<p>The absence of input in these arenas is underscored in the choice of key informants, as follows: “The Key Informants included two caregiver advocates and seven providers who are experts in palliative care and assessment tools in areas including oncology, pediatrics, critical care, health services research, outcomes research, palliative care quality measures, palliative care, clinical trials, and assessment tool development.” You will note that there is no one from geriatrics, long-term care, home care, or neurology. Curiously, the next section reports, “Both advocates reported that they had completed numerous written questionnaires with ‘tons of questions’ that ‘always felt rushed.’” These comments are very likely to be reporting experience with OASIS and MDS, which patients and caregivers routinely encounter in home care or nursing home care. Ironically, perhaps, neither of these instruments, nor the domains they cover, was included in the scope of this report.</p>	<p>In the final report, the key informants are listed by name, and they did include expertise in geriatrics, long-term care, and home care. We have added “geriatrics and hospice” to the description of the key informants in the results.</p> <p>We have expanded the next section of the results as suggested by an earlier reviewer to clarify the reporting experience: “Both caregivers reported that they had completed numerous written questionnaires with “tons of questions,” which overwhelmed them and became so granular that the caregivers felt they could not provide an accurate depiction of their experience and the issues that mattered most to them. Caregivers also felt that the way the assessments were administered “always felt rushed” in that they did not have time to reflect on the questions and often just indicated “their initial thoughts” or just “bubbled in an answer. They felt that the information captured in the tools was meaningful to clinicians, but they were not convinced that the tools had an impact on patients or families. To enhance the efficacy of detailed assessment tools, the advocates suggested that any encounter or survey should start with a question to identify the patient or family member’s unique “biggest concern,” and surveys or questionnaires should ultimately empower the patient or family member to “say what is on his or her mind.” For example, one caregiver supported her mother while she took care of her stepfather. The mother’s biggest concern was learning how she could keep her husband at home until the end of his life; this concern was not otherwise a priority for the physician.”</p>

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				<p>The report only covers assessment tools developed for or specifically tested in palliative care, so OASIS and MDS were not included.</p>
157	Public Comments #3 (Altarum Institute)	General Comments	<p>Indeed, in order to capture the quality of services rendered to a person living with serious advanced illness occasioned by frailty, dementia, or any other long-term disabling (and eventually fatal) condition, the instruments probably have to address care across time and settings. This requirement escaped the Consensus Project participants, because they were mainly concerned with hospital-based decision-making and symptom control in persons living with cancer and similar conditions. However, once one seriously considers the full range of people living with “serious advanced illnesses,” the issues that become priorities include some that stretch across conventional boundaries of setting or disease, such as alignment of the care plan with personal priorities, confidence in the care system for back-up with potentially urgent issues, seamless transitions, prudent spending of private assets, and long-term caregiver support.</p> <p>Even within the scope that the draft report addresses, there is a broader dimension that deserves to be identified. The report deals with how well palliative care addresses the domains identified by the Consensus Project report for the persons served by palliative care. However, the aim of providing palliative care has to include improving the experience of all persons living with serious advanced illness and their families, whether or not they actually have a palliative care practitioner directly involved. If having a palliative care service that interacts with a minority of the affected patients actually worsens the attention paid to the experience of other patients, the overall experience might worsen. This calls for measurement of the experience of a population, not just those directly served. Again, this is a gap that is not identified, as a direct result of the method chosen. In short, the report urgently needs to be honest and diligent about its limited scope. Otherwise, it is seriously deficient in addressing the domains of most importance to (most) persons living with serious advanced illnesses.</p>	<p>We agree, and have added to next steps, “Further research should also address use of assessment tools longitudinally and across settings and populations.”</p> <p>The report did not focus at all on the use of palliative care. The patient experience tools included did not require or assess palliative care services involvement.</p> <p>We have added to the new limitations section, “Using the National Consensus Project Guidelines as a framework for the domains and limiting to tools evaluated in palliative care populations excluded some types of tools that may be relevant in some applications in palliative care populations. We also recognize that other definitions of palliative care exist, and the tools covered in this report do not cover the full scope of potentially relevant populations.”</p>
158	Public comments #4 (National Coalition for	General Comments	<p>This report provides much-needed guidance on potential areas to focus for future measurement development. However, it does not provide a roadmap forward. The</p>	<p>Thank you for your comment. We have added to the next steps section, “Other organizations may use the survey of tools in this report to provide more specific</p>

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	Hospice and Palliative Care— Amy Melnick)		Coalition seeks AHRQ’s leadership to focus future efforts in determining how best to realistically address these gaps, provide detailed recommendations as to whom would fund these initiatives, and which organizations are best poised to accomplish this work.	recommendations for tools; consensus work to recommend tools would be helpful for researchers in palliative care.”
159	Public comments #4 (National Coalition for Hospice and Palliative Care— Amy Melnick)	General Comments	The technical brief could include mention of the following efforts that are underway that could assist with this work: National Quality Forum Palliative and End-of-Life Care Standing Committee National Quality Partners Advanced Illness Care project IMPACT Act Standardized Data Assessment Pew Research Center Improving End of Life Care through their “Building Additional Serious Illness Quality Measures into Medicare” project.	Thank you for your comment. This report focuses on the psychometrics of assessment tools and not ongoing policy work in quality indicators. We have clarified the definition of assessment tools to make this clearer.
160	Public Comments #5 (Hospice and Palliative Care Nurses Association— Marianne Matzo)	General Comments	Overall, this report provides much-needed guidance on areas to focus future measurement development. There are significant leadership opportunities for hospice and palliative nurses in this future work, which would ultimately benefit our patients.	Thank you for your comments